

# Living with **ALZHEIMER'S DISEASE**

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# INTRODUCTION

**Each year the number of people with Alzheimer's disease increases.** Currently, an estimated 5 million Americans and 26 million people worldwide are living with this degenerative brain disorder. Already, as many as one out of two people age 85 and older in the U.S. may have Alzheimer's, and this age group is one of the fastest growing segments of the population. By the year 2050, up to 15 million Americans could be affected.

In the past, there were many misconceptions about Alzheimer's disease. The symptoms were thought to be an inevitable and usual part of growing old. Although mild memory delays and forgetfulness are often associated with the elderly, these should not be confused with Alzheimer's progressive deterioration which involves a range of symptoms that go beyond mere memory lapses. We now understand that Alzheimer's is a specific disease primarily connected with aging.

In 1906, the German physician Alois Alzheimer first identified, through an autopsy of one of his patients, a collection of plaques surrounding the brain's nerve cells and tangled fibers within them. This disease would eventually bear his name. Since its discovery more than 100 years ago, there have been many scientific breakthroughs in Alzheimer's disease research. In the 1960s, scientists discovered a link between cognitive decline and the number of plaques and tangles in the brain. The medical community then formally recognized Alzheimer's as a disease and not a normal part of aging. In the 1970s, scientists made great strides







in understanding the human body as a whole, and Alzheimer's emerged as a significant area of research interest. This increased attention led in the 1990s to important discoveries and a better understanding of complex nerve cells in the brains of Alzheimer's patients. More research was done on Alzheimer's susceptibility genes, and several drugs were approved to treat the cognitive symptoms of the disease.

Over the last decade, scientists have made substantial progress in understanding potential environmental, genetic and other risk factors for Alzheimer's disease, and the processes leading to formation of plaques and tangles in the brain. Specific genes related to both the early-onset and late-onset forms of Alzheimer's have been identified, and more effective treatment options have been approved by the U.S. Food and Drug Administration (FDA). However, Alzheimer's disease is still incurable. The drugs currently in use treat only the symptoms, not the cause of the disorder, and they only temporarily slow the progression of cognitive decline.

As our understanding and knowledge of Alzheimer's disease enters the second century since its discovery, scientists are honing in on the possible root causes of the disease. More highly effective drugs with fewer side effects should emerge over the next several years. These drugs may not prevent or reverse the disease, but could act to substantially slow its progress. Furthermore, through increased investment in research, the road to a breakthrough discovery leading to a cure may be shorter than we think.

The Resource List at the end of this booklet has information on organizations that can help deal with many aspects of Alzheimer's disease, including caregiving, long-term care facilities, financial and legal issues, and clinical trials.

# Alzheimer's Disease – DESCRIPTION, RISK FACTORS AND MITIGATING RISK

## Description

**Alzheimer's disease irreversibly destroys brain function and eventually leads to complete brain failure.** During an autopsy, when scientists examine the brains of people with Alzheimer's under a microscope, they see two types of abnormalities: neuritic plaques outside the brain's nerve cells or neurons and neurofibrillary tangles within the neurons. Neuritic plaques are spherical structures consisting of a protein called beta amyloid and cellular material. Neurofibrillary tangles are twisted fibers of another protein called tau. These plaques and tangles, the hallmarks of Alzheimer's disease, seem to interfere with communication among neurons in the brain, thereby disrupting mental activity. This loss of connection appears to damage the functioning of these neurons and leads to their eventual death. Scientists are not entirely sure whether these plaques and tangles are a cause of Alzheimer's or are caused by it. However, much research is focused on stopping the accumulation of these proteins or preventing them from turning toxic.

Brain images of those with Alzheimer's disease show degeneration in regions vital to memory formation, which explains why Alzheimer's patients have trouble learning new facts and retaining short-term memories. Later in the disease, these images also reveal degeneration of the frontal lobe, which acts as the “executive” of the brain. Alzheimer's disease affects a person's cognition — the process of knowing — including awareness, perception, reasoning and judgment, as well as personality, behavior and communication. As the frontal lobe deteriorates, the individual exhibits symptoms such as poor organization and planning, distractibility, irritability and apathy.

## Known Risk Factors

Scientists have identified factors that appear to play a role in the development of Alzheimer's, but have not yet reached any firm conclusions as to the exact causes of this complex disease. There are likely many contributing factors, rather than one single cause.

**Age:** The single greatest risk of developing Alzheimer's is age. Approximately five percent of Americans between the ages of 65 and 74 are thought to have Alzheimer's disease; for those age 85 and older, the estimates range from thirty-five percent to nearly half.

**Genetics:** The majority of Alzheimer's cases are late-onset, usually developing after age 65. Late-onset Alzheimer's disease has no known cause and shows no obvious inheritance pattern. However, in some families, clusters of cases are seen. A gene called Apolipoprotein E (ApoE) appears to be a risk factor for the late-onset form of Alzheimer's disease. There are three forms of this gene: ApoE2, ApoE3 and ApoE4. Roughly one in four Americans has ApoE4 and one in twenty has ApoE2. While inheritance of ApoE4 increases the risk of developing Alzheimer's, ApoE2 substantially protects against the disease. Some current research is focused on the association between these two forms of ApoE and Alzheimer's. Familial Alzheimer's disease (FAD) or early-onset Alzheimer's is an inherited, rare form of the disease, affecting less than 10 percent of Alzheimer's patients. FAD develops before age 65, in people as young as 35. It is caused by mutations of one of three genes on chromosomes 1, 14 and 21.

## Potential Contributing Factors

**Cardiovascular Disease:** Risk factors associated with heart disease and stroke, such as high blood pressure and high cholesterol, may also increase the risk of developing Alzheimer's disease. High blood pressure may damage blood vessels in the brain, disrupting regions that are important in decision-making, memory and verbal skills. This could contribute to the progression of Alzheimer's. High cholesterol may inhibit the ability of the blood to clear protein from the brain.

**Type 2 Diabetes:** There is growing evidence of a link between Alzheimer's disease and type 2 diabetes. In type 2 diabetes insulin does not work effectively to convert blood sugar into energy. This inefficiency results in production of higher levels of insulin and blood sugar which may harm the brain and contribute to the progression of Alzheimer's.

**Oxidative Damage:** Free radicals are unstable molecules that sometimes result from chemical reactions within cells. These molecules seek stability by attacking other molecules, which can harm cells and tissue and may contribute to the neuronal brain cell damage caused by Alzheimer's disease.





**Inflammation:** Inflammation is a natural, but sometimes harmful, healing bodily function in which immune cells rid tissues of dead cells and other waste products. As protein plaques develop in Alzheimer's disease, inflammation results, but it is not known whether this process is damaging and a cause of Alzheimer's, or part of an immune response attempting to contain the disease.

**Other Possible Risk Factors:** Some studies have implicated prior traumatic head injury, lower education level, stress and female gender as possible risk factors. Alzheimer's disease may also be associated with an immune system reaction or a virus.

## Mitigating Risk through a Healthy Lifestyle

While the known risk factors for Alzheimer's disease, aging and genetics, are not controllable, numerous studies indicate that a healthy lifestyle may lower the risk of developing Alzheimer's. It's important to keep the body and mind in good shape through nutrition and exercise, avoidance of smoking, controlling certain physical conditions, and engaging in mental and social activities.

**Diet:** Eat a varied diet that includes plenty of fruits and vegetables, legumes (for example, beans, peas, and seeds), fruits, whole grain and fish, and is low in saturated fat and added sugar. Foods that contain omega-3 fatty acids, such as tuna and salmon, certain oils, nuts and seeds, and the antioxidant vitamins A, C and E may also be beneficial.

**Exercise:** Physical activity reduces the risk of many diseases, helps maintain a healthy weight and enhances mental fitness. A combination of moderately intense aerobic exercise, strength training, and activity that increases flexibility is recommended.

**Physical conditions:** Research has shown that vascular disease, stroke, high blood pressure, high cholesterol and diabetes may all be associated with an increased risk of developing or worsening Alzheimer's. Control these conditions if they are already present, and if they have not developed, avoid them through diet and exercise. Depression and stress can lead to physical problems and have also been linked to Alzheimer's, so they should be treated if necessary.



**Social connections:** Maintain and increase social connections with family and friends through creative and intellectual pursuits, such as crafts and hobbies, playing cards and games, attending plays, musical performances and lectures, and visiting parks and museums.

**Mental activity:** Build up brain "reserves" by continuing to enjoy favorite pastimes and engaging in new and challenging activities such as: playing board, card and video games; solving puzzles; reading, writing and corresponding; and even conversing and singing. Take a class, learn to play a musical instrument or begin a hobby.



Currently, there is no known treatment that will cure Alzheimer's disease. However, there are medications that can help control its symptoms.

# Alzheimer's Disease – DIAGNOSIS, STAGES, TREATMENT AND RESEARCH

## Diagnosing Alzheimer's Disease

**Many people recently diagnosed with Alzheimer's may have felt for some time that "something isn't right."** They may have become more forgetful, found themselves easily disoriented, had unexpected lapses in judgment, or experienced unusual mood swings and emotions. These can be early signs of dementia, but they can also be signs of depression or other treatable conditions. In addition, some dementias are caused by dehydration, drug reactions, hypothyroidism, infection or other physical problems; these dementias can be reversed. A physician, through a complete examination, can rule out other conditions with similar, Alzheimer's-like symptoms. Although a true diagnosis can only be made by doing a brain autopsy, through examination and testing, physicians can correctly diagnose Alzheimer's disease in nine out of 10 cases. Early diagnosis and treatment are important because current drugs appear to be most effective at slowing cognitive decline when taken in the first stages of the disease.

A thorough evaluation for Alzheimer's disease will include physical, neurological and psychological testing: a physical examination, including testing of blood and urine, as well as liver and thyroid function; memory, language, problem solving, attention and counting tests; depression screening; and brain imaging.

## Stages of Alzheimer's Disease

The following are some common early symptoms of Alzheimer's: confusion, disturbances in short-term memory, problems with attention and spatial orientation, personality changes, language difficulties and un-

explained mood swings. Recently, scientists have identified a condition between normal age-related memory loss and dementia called mild cognitive impairment (MCI). Individuals with MCI have persistent memory problems (for example, difficulty remembering names and following conversations and marked forgetfulness) but are able to perform routine activities without more than usual assistance. MCI often leads to Alzheimer's, but while all those who progress to some form of dementia go through a period of MCI, not all patients exhibiting MCI will develop Alzheimer's disease.

Anywhere from three to 15 stages and sub-stages have been identified for Alzheimer's disease. The three



stages listed below represent the general progression of the disease. However, Alzheimer's disease does not affect everyone in the same way, so these symptoms will likely vary in severity and chronology. There will be fluctuations, even daily, and overlap of symptoms. Some people will experience many symptoms, others only a few, but the overall progress of the disease is fairly predictable. On average, Alzheimer's patients live for eight to 10 years after diagnosis, but this terminal disease can last for as long as 20 years.

In all stages, symptoms generally relate to progressive impairment of mental processes and memory function, communication problems, personality changes, erratic behavior, dependence and loss of control over bodily functions.

**Stage 1 (Mild):** This stage can last from two to four years. Early in the illness, those with Alzheimer's disease tend to have less energy and spontaneity, though often this goes unnoticed. They exhibit minor memory loss, depression and mood swings, and are slow to learn and react. After a while they begin to avoid people and new places and prefer the familiar. Individuals become confused, get lost easily and exercise poor judgment. They may have difficulty performing routine tasks, and have trouble communicating and understanding written material. This can lead to exhibitions of anger and frustration. If the person is employed, memory loss may begin to affect job performance.

**Stage 2 (Moderate):** This is generally the longest stage, and can last two to 10 years. In this stage, the person with Alzheimer's is clearly becoming disabled. Individuals can still perform simple tasks independently, but may need assistance with more complicated activities. They are forgetting recent events and their history, and becoming more disoriented and disconnected from reality. Memories of the distant past may be confused with the present, and affect the person's ability to comprehend the current situation, date and time. They may have trouble recognizing familiar people. Instructions must be clear and repeated often. Speech problems arise and understanding, reading and writing are more difficult. They may no longer be safe alone and can wander. As Alzheimer's patients become aware of this loss of control, they may become depressed, irritable and restless, or apathetic and withdrawn. They can experience sleep disturbances and have more trouble eating, grooming and dressing.

**Stage 3 (Severe):** This stage may last one to three years. During this final stage, people may lose the ability to feed themselves, speak, recognize people and control bodily functions. Their memory worsens and may become almost non-existent. Constant care is typically necessary. In a weakened physical state, patients may become vulnerable to other illnesses and respiratory problems, particularly when they are unable to move around.

## Current Medical Treatments for the Symptoms of Alzheimer's Disease

Currently, there is no known treatment that will cure Alzheimer's disease. However, there are medications that can help control its symptoms. In addition, medical treatments are also available to help manage agitation, depression or psychotic behavior (hallucinations or delusions), which may occur as the disease progresses. Before taking any medications, over-the-counter drugs, supplements or herbs, consult a physician for a thorough evaluation in order to make an informed decision.

There are five FDA-approved drugs used to treat Alzheimer's disease. Four of them, called cholinesterase inhibitors, are designed to regulate symptoms and delay the course of Alzheimer's: Cognex® (tacrine); Aricept® (donepezil); Exelon® (rivastigmine); and Razadyne® (galantamine). These drugs slow the metabolic breakdown of acetylcholine, an important brain chemical involved in nerve cell communication. Those suffering from Alzheimer's have low levels of acetylcholine, and these drugs make more of it available for communication between cells. This may help slow the progression of cognitive impairment and can be temporarily effective for some patients with Alzheimer's. However, as Alzheimer's disease further develops, less acetylcholine is produced and the drugs tend to lose their efficacy.

All four of the above medications are approved for the treatment of mild to moderate symptoms of Alzheimer's disease in its early stages, and are aimed at slowing degeneration and even improving mental function, including thinking, judgment, recognition and memory. Effectiveness and results vary from person to person, and some drugs may be better tolerated than others by certain individuals. Side effects can include nausea, dizziness, headache, fatigue, insomnia, muscle cramps and weight loss.



Cognex, though effective, has more adverse side effects than the other medications and although still available, is now rarely prescribed. Aricept appears to have a limited, but slowing effect on the progression from MCI to Alzheimer's. Individuals with MCI have memory problems, but are able to independently perform daily activities; however MCI often leads to Alzheimer's disease. In 2006, the FDA also approved Aricept for the management of severe Alzheimer's symptoms.

Namenda® (memantine) is the fifth FDA-approved drug and is used for the treatment of moderate to severe Alzheimer's. Namenda is an N-Methyl-D-Aspartate (NMDA) receptor antagonist. NMDA receptors control the actions of a chemical messenger called glutamate that is released in large amounts by Alzheimer's-damaged brain cells. Namenda appears to protect the nerve cells against excess amounts of glutamate. Side effects may include fatigue, dizziness and headache.

All of these Alzheimer's drugs are administered orally. However, in 2007, the FDA approved the use of an Exelon patch that delivers medication through the skin. Aricept, Razadyne, Exelon (oral form) and Namenda all cost approximately the same, around \$200 per month (Consumer Reports, [www.medicalguide.org](http://www.medicalguide.org), based on nationwide retail average in September 2006).

Depression is common in the early stage of Alzheimer's, and it can be treated. For individuals in the middle stages of the disease, there are also medications to control depression, anxiety and psychotic behavior, including paranoid thoughts, delusions and hallucinations. The patient can also become agitated and resistant to care, which may escalate into combativeness. Medications for these symptoms are considered when non-medication alternatives have failed and/or these symptoms put the person with Alzheimer's or others in danger.

## **Research on Potential Treatments for Alzheimer's Disease**

There is a strong Alzheimer's disease research community, and many potential

treatments are being investigated through work in laboratories as well as in human clinical trials. Scientists continue basic research on therapies that could potentially clear the protein plaques in the brain. The safety and efficacy of possible treatments are being tested on humans, including drugs that could remove plaques, immunotherapy (vaccination) with beta amyloid antibodies, non-steroidal anti-inflammatory drugs (NSAIDs) and statins (drugs used to lower cholesterol). The protective effects of antioxidants (Vitamins A, C and E) and omega-3 fatty acids (found mainly in fish such as tuna and salmon) are also being tested in trials. To date, no consistent results have emerged from various studies, but further research and future results from rigorous trials should help clarify the benefit of these and other treatments.





Those who have accepted the terminal nature of the disease normally find an inner peace and a greater sense of perspective. They are able to prepare themselves and their families and live much more fully.



# Emotional Impact OF DIAGNOSIS

**Upon a diagnosis of Alzheimer's, the individual and family members will need time to prepare emotionally for the progressive and terminal nature of this disease.** The person with Alzheimer's and loved ones will likely be overwhelmed and need time to absorb the news. Some of these initial emotions are described below.

## **Effect on Those with Alzheimer's Disease**

It may take time to work through the stages normally associated with the diagnosis of a terminal illness: denial and isolation; anger and resentment; bargaining; depression; and finally, acceptance. In moving through the stages of adjustment, patients need to reach out for support to family and friends, as well as professionals such as physicians and counselors. It often helps to talk to others with the disease in support groups. Many people worry less as they gather more information. Some patients derive comfort from spiritual consultation, and those who don't belong to formal religious groups can still gain insight and perspective from religious and philosophical texts. Formal counseling as well as heart-to-heart discussions with close friends can also be very helpful.

Those who have accepted the terminal nature of the disease normally find an inner peace and a greater sense of perspective. They are able to prepare themselves and their families and live much more fully. They realize there will be time to continue enjoying life, make important plans and decisions, engage in pleasurable activities and come to closure in many areas. Additionally, some individuals with mild Alzheimer's become

advocates for research and care through volunteer activities, speaking engagements and lobbying efforts.

Most recently diagnosed patients need to wait before telling family members about their illness. For some, letting others know may bring about a sense of finality to the diagnosis. Revealing this information to family members can be emotionally painful for all concerned, and everyone will need to process their own feelings about the illness. This is a difficult time, but generally individuals with Alzheimer's feel a sense of relief when the information is no longer concealed.

## **Effect on Family Members**

The patient's spouse will likely need to process strong emotions related to the diagnosis. Many times spouses also have to deal with their own health problems. They may fear a future that will be very different from the one they had planned. Husbands and wives often are required to reverse roles and take on unfamiliar tasks. Depending on their relationship, a diagnosis of Alzheimer's can bring couples closer together or it can alienate them. Spouses need to accept that the person they have known and loved may change dramatically in personality and behavior, and there will

almost without a doubt come a time when their loved one does not recognize them. The spouse may appreciate getting together to converse and to discuss these feelings. He or she may seek offers of help with meals, transportation and other tasks, as well as simple, kind acts such as visits and respite. Caregiver training and support groups can also be very helpful and are recommended. In some cases, professional counseling may be needed.

Adult children will also need to adjust to the role reversal in caring for their parent. They may feel overwhelmed by the looming responsibilities of working within or outside the home, caring for their own children and helping their parent. Children who do not live close by may feel guilty, not fully comprehend or perhaps even deny the realities of the disease. However, family members should support the main caregiver

and try to help with tasks that do not require proximity. As distressing as a parent's Alzheimer's diagnosis can be, this is the time to begin to accept the future, build a support network, gather information to help alleviate fears, and plan for the road ahead.

Children and adolescents are affected by Alzheimer's as well and may feel sad, frustrated, angry or afraid if someone in the family, a grandparent for example, is diagnosed. Younger family members should be encouraged to ask questions and express feelings, and they should be honestly addressed. They need to understand that although the loved one may act differently, there are still activities they can enjoy with their relative, such as helping with chores, listening to music or reading a book. Teachers and guidance counselors should be made aware of the situation. There are also books and support groups that deal specifically with young people.





# Planning FOR THE FUTURE

**The amount of time it takes to adjust to a diagnosis of Alzheimer's will vary from person to person, both for those with the disease as well as their loved ones.** Open communication and information sharing among everyone involved can help determine when the time is right to begin planning for the future. Certain matters should be taken care of as quickly as possible, and although it may seem daunting, breaking down tasks and dividing responsibilities can alleviate some stress.

As a starting point, family members may want to meet together with the patient to discuss his or her needs and wants, decide on a care plan, sort responsibilities, build a support network and find outside resources. A mediator or objective third party can be helpful. Although they do charge a fee, the family may consider hiring a professional geriatric care manager (GCM) who can evaluate the situation and identify solutions for various aspects of long-term care. Generally, these care managers charge an intake fee (\$50-300) and an hourly rate of \$50-200 depending on location, qualifications and extent of services. Some organizations may subsidize the cost. The Resource List includes information on finding GCMs.

A long range plan should include gathering important financial, legal and health information, identifying responsibilities, finalizing legal documents (advance directives), and a discussion of long-term caregiving options.

## Employment

If they are working at the time of diagnosis, those with Alzheimer's should inform the appropriate su-

pervisors as soon as possible. If the person is having difficulties at work, telling the employer should relieve some of this pressure. A meeting with the human resources or benefits office is recommended to discuss insurance, retirement and disability plans. A specialist can explain the details of benefits, including any counseling or financial services that may be available. Obtain a copy of any explanation of benefits for future reference, and make certain that a family member or future caregiver also has a copy of all information. Discuss with the human resources office any rights those with Alzheimer's may have under the Americans with Disabilities Act. Caregivers should investigate whether they can take leave from work under the Family Medical Leave Act.

## Gathering Important Information

Soon after a diagnosis, financial, legal and health records need to be put in order. The following information should be gathered and kept together in a single place that is known to at least two family members, caregivers or trusted friends.

## General

- Name, address and Social Security number
- Driver's license, passport, birth certificate and marriage certificate
- Insurance information, including Medicare and Medicaid numbers and life, health, homeowner's and automobile policies and policy numbers
- Veterans Administration claim number, if applicable
- Names, addresses and phone numbers of lawyers, financial advisors or accountants, and insurance agents

## Financial

- Bank records, including all bank account numbers (Consider opening a joint checking account so that a spouse or caregiver can help pay bills and handle routine banking matters; arrange for direct deposit of Social Security and retirement income.)
- Information on all sources of income, including pension plans, IRAs, Keogh plans and stock certificates

## Tax records

- Information on property owned (including real estate), mortgage payments or titles to property
- Credit cards and account numbers, including personal identification numbers (PINs) and security codes
- Information on all loans or outstanding debts, and on money owed to the patient
- Receipts/documents for any pre-paid funeral/burial arrangements, if applicable

## Legal

- Copy of will or information on location of the will, advance medical directives, durable power of attorney for health and/or finances documentation; burial requests (mortuary, burial plot and deed)

## Health

- Names, addresses and phone numbers of physicians, hospitals, etc.
- Information pertaining to medical history, medications and dosages and medical devices



## Division of Responsibilities

To alleviate some of the stress of dealing with the future, the family may want to hold a meeting to discuss plans and division of caregiving responsibilities. No one can predict what will be needed for every stage of the disease, so emphasis should be on the immediate future, while considering possibilities for the longer term. Prior to the meeting, gather information and resources. Be sure to include the person with Alzheimer's in the discussions, but keep in mind that the individual may be resistant to suggestions and still overwhelmed emotionally. Other family members should allow him or her to express needs and desires, keep their minds open and make positive suggestions. Disagreements will almost inevitably occur, but everyone should be encouraged to voice their opinions and make recommendations.

Each member should honestly assess personal preferences, financial abilities and time availability to determine his or her appropriate role. Draft a written plan that includes decisions on allocating responsibilities (hands on and long distance), costs and time commitments. These responsibilities can be divided as follows: medical needs, including communication with physicians and keeping track of medical records; daily living activities (bathing, dressing, etc.), as well as cleaning, meal preparation, transportation and shopping; and financial and legal issues. Although a written plan is recommended, it should also be adaptable to the person's changing needs. Put a system in place to ensure essential, regular communication among family members.

As much as possible, family members should be supportive of one another, offer assistance and respite to the primary caregiver, and stay up to date on the physical and emotional condition of the person with Alzheimer's. They should take advantage of the many resources available for caregiver support, including those listed in the back of this booklet.

## Home Safety

The safety of the home can be a concern for some Alzheimer's patients, particularly if they begin to wander. The caregiver should do a room by room safety check and periodically reassess needs as the disease progresses. Not all changes need to be made immediately; some will be more appropriate in the later

stages of Alzheimer's. It is possible to modify and adapt the home while keeping the surroundings familiar and comfortable.

The following are general precautions:

- Keep important and emergency phone numbers handy.
- Ensure adequate lighting throughout the home; install night lights.
- Keep entryways, halls and floors free of clutter, extension cords and scatter rugs; avoid placing furniture in walking areas.
- Secure locks on windows and doors; keep a spare key hidden outside the home or give one to a neighbor or nearby friend.
- Use childproof locks for toxic substances, medications and alcohol.
- Ensure that smoke detectors are in working order.
- Install handrails on stairs, grab bars in bathrooms and other devices designed for those who need physical assistance.
- Remove and safely store potential hazards such as weapons, plastic bags and power tools.
- Protect computers and information stored on them.
- Consider investing in a sound monitor, such as those used with babies, unless it confuses the person.
- Consider labeling doors to rooms such as "bedroom," "bathroom," etc.
- Ensure that emergency plans are in place.

If the Alzheimer's patient begins to wander, extra precautions need to be taken to secure the home. Many companies offer safety devices such as double locks, alarms and items used to disguise exits. An identification or medical bracelet for the individual is also a good idea. Neighbors, local merchants and police should be notified in case the person manages to leave the home without a companion. The Resource List at the back of this booklet includes websites with more information and products for ensuring home safety.

## Driving Safety

Deciding when the person with Alzheimer's should stop driving can be difficult, and the situation should be calmly and positively discussed, ideally before problems arise. Many people in the very early stages of the disease may be able to continue driving safely, but even at this point, they should stay on familiar short routes in daylight and good weather. As the disease progresses,

driving ability needs to be carefully observed over a period of time and reassessed. Consider the person's reflexes, coordination, reaction time, eyesight, hearing and ability to orient him or herself. Habitual problems such as making slow decisions, failure to observe traffic signals and hitting curbs are warning signs. When driving becomes unsafe, it may be necessary to enlist an authority figure, such as a physician, to reinforce the decision. To ease the transition, investigate and offer alternative forms of transportation and reduce the number of activities that require driving. For example, prescriptions and groceries can be delivered rather than picked up at a store. Driving is often part of an individual's social life, so try to find other ways to continue these interactions, such as asking friends and family to visit. If the person insists on keeping the car keys, it may be necessary to give him or her keys that don't work, temporarily park the car elsewhere or disable the engine.

## Financial Matters

Planning for the financial future of Alzheimer's disease is extremely important. There are costs associated with medical professionals, prescriptions, assistance in or outside the home, and long-term living arrangements, all of which can add up and drain personal savings very quickly. As early as possible, gather information on all means of payment, and decide which are best. In addition, caregivers and other family members should review their own finances to determine whether and how much they can contribute. The recommendations below should not replace professional advice, and those affected should consider consulting a financial advisor. For a list of organizations that provide financial information and assistance for older Americans see the Resource List at the back of this booklet.

Some payment options include:

### Government benefits programs

**Medicare** is a federal health insurance program for people age 65 or older who are receiving Social Security retirement benefits. To receive Medicare assistance, specific eligibility requirements must be met. Medicare covers some, but not all, of the services a person with Alzheimer's may require. Prescription drug coverage is also available.

**Medicaid** is a federal program for certain individuals and families with low incomes and resources, typically administered by state agencies; eligibility

and benefits vary from state to state. Medicaid can cover all or a portion of nursing home costs, as well as some in home care. A person with Alzheimer's can qualify for long-term Medicaid coverage only if there are minimal income and cash assets, and should apply through the state's Department of Human Services or Medicaid Assistance Program.

**Social Security** is a federal program that provides retirement income, disability payments and other payments to workers who contributed to the plan when employed, and to their dependents.

**Veteran's benefit programs** may be applicable.

#### **Private insurance plans**

**Medigap** is health insurance sold by private companies to supplement, or fill the "gaps," in Medicare coverage.

**Managed care health insurance** includes preferred provider plans and health maintenance organizations.

**Long-term care insurance** is an option only if it is in place at the time of an Alzheimer's diagnosis.

#### **Loans and personal savings**

**Life insurance policies** – there are several ways to obtain loans from these policies that do not have to be repaid until death.

**Mortgages** – it is possible to borrow money against the equity in a home through a reverse mortgage.

**Personal assets** – these can include income from stocks and bonds, sale of property, savings accounts and retirement accounts.

## **Legal Matters**

Ideally, the legal documents described below will be in place before a diagnosis of Alzheimer's. If not, the patient and a caregiver or companion should consult a lawyer as soon as possible because these instruments cannot be completed if a person is declared legally incompetent. Those in the early stages of the disease are not automatically assumed to be incompetent, and they will probably be able to understand the issues and make decisions. However, if a court determines that the person is incompetent, family and friends may be

able to manage affairs, but more than likely the court will need to appoint a surrogate to legally act on behalf of the individual with Alzheimer's.

*The information provided below contains general statements and does not constitute legal advice.* For legal advice, a family lawyer may be retained, but there are also attorneys who specialize in elder law. Lawyers can help interpret state laws and ensure that the wishes of the patient are carried out. Elder law attorneys are experts in legal matters of the aging such as long-term care, Medicare, Medicaid, taxes and estate planning. Local Agencies on Aging may be able to provide referrals for legal advice, and low cost legal services are available through state legal aid societies. The Resource List at the end of this booklet contains more information on elder law attorneys and legal assistance.

Although newly diagnosed people will likely be emotionally distressed, they should still be encouraged to actively participate in these legal discussions. This may lead to a sense of greater control and calmness. Those who may already be slightly impaired should be involved as much as possible, and will likely be capable of making at least some decisions. If the Alzheimer's patient resists taking action, a strong, but understanding family member, good friend or objective professional may be required to ensure a secure legal future. In all cases, individuals with Alzheimer's need to be extremely careful in choosing those who will act as their agents, and in deciding which powers will be granted.

If not already completed, legal medical directives should include establishing a Durable Power of Attorney for Health Care and completing a living will. Legal financial documents – a Durable Power of Attorney for Finances, a will and possibly a living trust — also need to be finalized if they are not already in place. These documents should be revisited periodically to ensure they are up to date. Since state laws vary, if the person moves, the documents may need to be re-examined. Family members or caregivers should know where the originals are located and have copies; the patient's physician should have copies of health-related legal documents.

## **Advance Medical Directives**

A **Durable Power of Attorney for Health Care** document must be drawn up before the patient becomes incapacitated. A Durable Power of Attorney for Health



Care allows the patient to appoint a trusted person to make medical and health decisions when the individual can no longer do so. Some documents go into effect immediately, while others “spring” into action when a specified event occurs. It is important to choose the “agent” carefully and to fully discuss detailed wishes. This agent should be someone who knows the patient very well, but who can also remain level-headed and flexible in the face of change and emotional stress. The individual who is selected must agree to take responsibility, may need to make final decisions on minor and major medical issues, including life support, and has the right to withdraw from the agreement. Appointing an alternate is advised in case the chosen person is not willing or able to carry out the duties.

**Living wills** allow patients, while they are still able, to decide upon and express their wishes regarding end of life care. Later, they may no longer be capable of communicating these desires. With a living will, the patient can carefully consider what measures should be taken to prolong life. Often, specifying these actions eases the emotional burden of the loved ones. A living will may contain a “Do Not Resuscitate” order and other treatment limitations that instruct health care personnel not to perform aggressive medical interventions in situations where they could be used. If a physician or facility cannot honor a living will, they must inform the patient or the patient’s representative, and assist in transferring the patient to a facility that will honor it.

## Finance-related Documents

In establishing a **Durable Power of Attorney for Finances**, the individual authorizes a family member, friend or professional to act as an agent or proxy on his or her behalf in making financial decisions including banking, investments, and tax and retirement matters. While the individual can direct his or her proxy, it is imperative that this person is carefully chosen, is trustworthy and exercises good judgment, especially as the Alzheimer’s patient becomes incapacitated.

If the person with Alzheimer’s becomes legally incompetent before a Durable Power of Attorney for Finances can be named or if there is disagreement regarding the proxy, a **conservatorship** may have to

be established through the court to handle financial matters. Although it has the advantage of legal supervision, a conservatorship can be expensive and time consuming to establish, requiring an investigation into competency, a hearing and a judgment. It is normally easier and quicker to establish a Durable Power of Attorney for Finances as soon as possible. A conservator does not make health decisions.

A **will** details how an individual’s assets and estate will be divided upon death. Since the person must be of sound mind, a will should ideally be in place before an Alzheimer’s diagnosis. A newly diagnosed patient, family member or professional should ensure that a will has been completed and is up to date. In the absence of a will, each state determines distribution of assets, which typically go to spouses, children or other family members. Some people choose to establish a living trust to distribute assets after death. A **living trust** is established while the individual is alive. The “grantor” (i.e., the person with Alzheimer’s) designates someone to serve as the trustee. The trustee manages assets of the trust and ensures proper distribution of them after the grantor’s death.





Usually, the primary caregiver will be a loved one – a spouse, adult child or close companion. Even in the early stages of Alzheimer’s, caregiving is an extremely demanding, 24-hour-a-day task.

# CAREGIVING

## For Those Who Live Alone

**Some patients continue to live alone in the early stages of Alzheimer's.** If so, family members, friends or neighbors should check on the person daily to see if assistance is needed. Someone close should have an extra set of house keys as well as emergency contact information.

There are a variety of services available for those with Alzheimer's who live by themselves. These include in-home assistance, housekeeping, meal preparation and transportation. Family members, friends, neighbors, local religious organizations and community volunteer groups can help with other practical matters such as shopping and medical appointments. Physicians, local Agencies on Aging, as well as organizations listed at the back of this booklet can provide information on available services.

At some point, the person with Alzheimer's will be unable to perform daily tasks and require more care and supervision. This will usually be determined by those who are in closest contact, but they may want to ask others to help discuss plans with the Alzheimer's patient. It is best to carefully consider long-term care options as early as possible, before a serious event forces a less than ideal choice. Safety is paramount, and once it is apparent that the person with Alzheimer's is not safe living alone, there should be a transition to a place that offers



more assistance. If the person resists a transfer, it may be helpful to create an excuse (e.g., work is being done on the home) or persuade him or her that the situation is temporary (even though it is permanent).

## Staying Active

Keeping active on all levels can be helpful to those with Alzheimer's disease. Although some

newly diagnosed patients may want to withdraw from their usual activities out of depression or embarrassment, this can actually worsen a person's condition. People need to recognize their limitations, but can prolong the quality of life by maintaining a healthy level of stimulation physically, mentally and socially, and avoiding stress, which can tax memory and concentration.



Suggestions for beneficial activities:

- Interact with others, including family, friends, children and pets. Visitors can provide an appreciated human connection.
- Get involved in a support group.\*
- Engage in creative activities, favorite pastimes and hobbies; play games and solve puzzles.
- Listen to music, which can have a calming effect and trigger vivid memories of the past; sing familiar tunes.
- Look at photographs and home videos, which can stimulate the mind, elicit memories and offer a calming sense of continuity.
- Perform simple household tasks that do not rely too much on memory, like meal preparation, gardening or light cleaning.
- Take part in activities such as being taken for a drive, going on nature outings or to the zoo, and visiting quiet museums or art galleries. These should be shared with a companion who can ensure safety.
- Initiate or continue a light, regular exercise routine.

*\* Support groups can be helpful for those with Alzheimer's disease. In these groups, people often are better able to come to grips with this disease and the future by expressing their feelings and thoughts with others. For many Alzheimer's patients, support groups help to "digest" the news of the diagnosis, overcome denial and adjust to the changes in their lives. Support groups offer practical advice on dealing with memory loss, social situations and adjustments in day-to-day living, and information on community resources. They may offer activities designed to stimulate memory and keep the mind active. These groups can contribute greatly to the quality of life.*

## Role of the Caregiver

Usually, the primary caregiver will be a loved one – a spouse, adult child or close companion. Even in the early stages of Alzheimer's, caregiving is an extremely demanding, 24-hour-a-day task. Caregivers need to be flexible and understanding in dealing with changes in behavior and personality. They must also be able to communicate with family, friends and professionals about their loved one's condition.

Many resources and books offer advice on dealing with those who have Alzheimer's disease — keep these

resources handy (many can be found at the end of this booklet). In some communities, caregiver consultation and counseling is available. Although each individual is different, there are many strategies that can be used to make life easier for both the patient and the caregiver. These recommendations include:

- Compensate for changing capacities and assist in remembering information. Memory aids such as small books with names, addresses, phone numbers, directions, maps and ideas can all be useful. The patient or caregiver can label items around the house, post reminders for daily tasks, keep calendars with appointments, and photos with information about those pictured.
- Maintain contact with the Alzheimer's patient's physician with regular updates on any changes in routine, behavior or moods. Ongoing or new treatments for Alzheimer's disease and associated symptoms, as well as therapy for other medical issues should be discussed. The patient and family may also want to consider participating in clinical trials testing new Alzheimer's treatments or investigating Alzheimer's disease-related issues. Information about ongoing trials can be found on the websites listed in the back of this booklet.
- Establish routines. For those with Alzheimer's disease, the familiar is calming, and they may enjoy simple, repetitive tasks. Ensure that they can "succeed" at these to reduce frustration.
- Speak clearly and simply while looking the person in the eye; give easily understood instructions in a normal tone of voice.
- Try to engage the person in simple activities that build on current skills, rather than attempting to teach new ones. The patient will likely continue to be interested in and enjoy familiar pastimes. Keep in mind that some times of the day are better for proposing activities, and the individual should not be forced into doing anything. Mental state can also change from day to day.
- Use "validation" to enter the person's world. It is very unlikely that the caregiver or anyone else will be able to change the patient's concept of reality. It is much easier to respond positively rather than try to correct misconceptions. Avoid arguing with the person as it will only frustrate both the patient and the caregiver.



- Use redirection and distraction if the person wishes to do something that is not possible (e.g., drive a car). Often, presenting a more appealing option will succeed.
- Avoid situations such as noisy crowds and environmental factors like violent TV programs that may frighten or agitate the person. Often agitation is a way of communicating stress, and modifying the atmosphere may change the behavior.

## Caregiver Stress

Fulfilling and adapting to the changing needs of the person with Alzheimer's, dealing with unfamiliar behavior and practical matters, and handling the grief of eventual loss takes a physical and emotional toll on caregivers. Those with Alzheimer's and their caregivers should discuss with each other the many aspects of this disease as soon as possible. Early communication can help alleviate the caregiver's guilt and frustration in the future. However, even in the best circumstances, caregivers often become both physically and emotionally exhausted, making them susceptible to illness and depression. To avoid this, caregivers need to focus on their own health and recognize the signs of stress. They may experience denial, depression, irritability, anger and anxiety, as well as physical warnings such as trouble sleeping, exhaustion and health problems. There are many ways to relieve pressure and reduce the stress of caregiving, some of which include: take time out to relax, engage in an enjoyable pastime, keep a list of tasks, write in a journal, maintain a sense of humor, eat right, exercise and get proper rest. Caregivers deserve to give themselves credit for doing the best they can in a very trying situation.

As the disease progresses, the individual with Alzheimer's will become more dependent and less able to participate in many activities. The primary caregiver may become resentful, feel underappreciated and isolated. Therefore, any encouragement, emotional support and social interaction family and friends can provide the caregiver is especially important to help avert these negative feelings. The caregiver should be able to turn to receptive family members, friends or professionals for practical assistance as well. Those close to the caregiver need to provide necessary respite and share in caregiving as much as possible. Out of town family members should regularly communicate and offer to help with those responsibilities that can be undertaken from a distance. In this way, the caregiver will establish a support network of resources.



## Support Groups

Many caregivers can greatly benefit from participation in support groups, some of which meet physically on a regular basis and others that interact virtually on the internet. Both offer advice, information, resources and comfort. Sometimes family members and friends are not as responsive or sympathetic as the caregiver would like. Those in support groups may have a greater understanding because they are in similar situations. Many become like family or close friends as they discuss common problems, coping strategies and caring for oneself as well as the Alzheimer's patient. Many support groups can be located using the Resource List in this booklet.

## Caregiving Options for the Future

There are several caregiving options that may be divided into two categories: short-term care offered in the home or temporary care outside the home, and long-term care facilities. It is important to plan caregiving early and take into consideration the desires of the person with Alzheimer's, the current and anticipated necessary levels of care, as well as location and budget constraints. Financial assistance may be available for some short-term care services. However, Medicare does not cover long-term care, so these types of facilities must be financed through private insurance plans, loans and personal savings. If these funds are depleted, Medicaid may be used to pay for continued care. Although the cost will fluctuate depending on real estate market trends, location and the level of services or amenities, long-term care is expensive. The entire financial situation needs to be carefully evaluated to determine available resources. Organizations listed at the back of this booklet offer more information on each type of care, how to assess what type is needed for the individual, and locating and evaluating facilities.



## Short-Term and Temporary Care

**Home Health Agencies** provide support services to the Alzheimer's patient in the home and access to outside care if necessary. Services can include skilled care such as rehabilitation and administering injections, custodial care (cleaning, meal preparation, etc.), companionship and transportation. Medicare does not cover this type of care, which can cost \$15-50 per hour depending on the type of assistance. When deciding, check into licensing, staff credentials, whether the agency provides the needed level of care and is affordable.

**Adult Day Centers** provide structured programs in which the patient is dropped off in the morning and picked up in the afternoon or evening. Participants can spend the day engaged in supervised activities such as games, craft projects and light exercise. Some programs also offer meals, transportation and

even professional services such as physical therapy. Adult day centers are often a pleasant prospect for both the patient and the caregiver, who may use the time to take a break from responsibility. The average cost is \$40-50/day, but can range from \$25-70/day depending on services. These programs must be paid for privately, but some may be subsidized.

## Long-Term Care

**Independent Living or Retirement Communities** are for seniors who are generally healthy and able to care for themselves, so these are not usually a long-term solution for those with Alzheimer's. They offer housing with recreational, educational and social activities geared specifically to older people. Meals, housekeeping, transportation and planned activities may also be available. Different communities can have a wide variety of amenities, including golf,

tennis, pools and fitness centers. The average cost of these communities ranges from \$1300-2500/month, depending on the size of housing, location, services and amenities. Most communities accept only private methods of payment, but there may be some subsidies for low-income individuals.

**Assisted Living Facilities** offer private rooms or apartments with in-house care and social activities for older people. Many have special sections for those with Alzheimer's, and are most appropriate for those in the early to mid stages of the disease, who need some regular assistance short of acute medical care. They can offer a home-like setting, 24-hour staff coverage, housekeeping and meal assistance, therapeutic activities and in-house medical services if needed. Depending on the size and location of housing and the level of care, the cost of assisted living facilities can range from \$1,000-6,000/month, with a national average of \$2,500-3,000/month.

**Life Care Communities or Continuing Care Retirement Communities** require a lifetime commitment. They begin as independent living facilities, but offer continued care to residents as they age and their needs change. The person must be able to live independently at first and can then be transferred from an apartment to an affiliated nursing home. Some of these communities have special programs for those with Alzheimer's. Normally, there is an entrance fee of between \$20,000-400,000, as well as monthly maintenance fees ranging from \$400-2,500.

**Nursing Homes or Skilled Nursing Facilities** offer long-term 24-hour care for people with late stage Alzheimer's. Many facilities have special sections for Alzheimer's patients. They provide rooms, meals, supervised activities and necessary therapy to residents. Nursing homes must be licensed by the state and certified by Medicare and Medicaid, thus they are subject to strict standards, inspections and evaluations. Medicare does not cover long-term care; Medicaid is available for those with low incomes or whose resources are exhausted. The average cost of a nursing home falls between \$3,000-6,000/month.

## Hospice Care

**Hospice Care** is available in the home or in a facility for those with terminal illnesses and six months or less

to live. In hospice, residents are treated for comfort, rather than to cure disease and prolong life. Hospices seek to preserve an individual's dignity and the highest quality of life for as long as possible. Medicare covers the cost of hospice care, and it is available to those with Alzheimer's. However, it is underutilized in these cases because it is difficult to determine how long the person will live.

## Choosing a Nursing Home

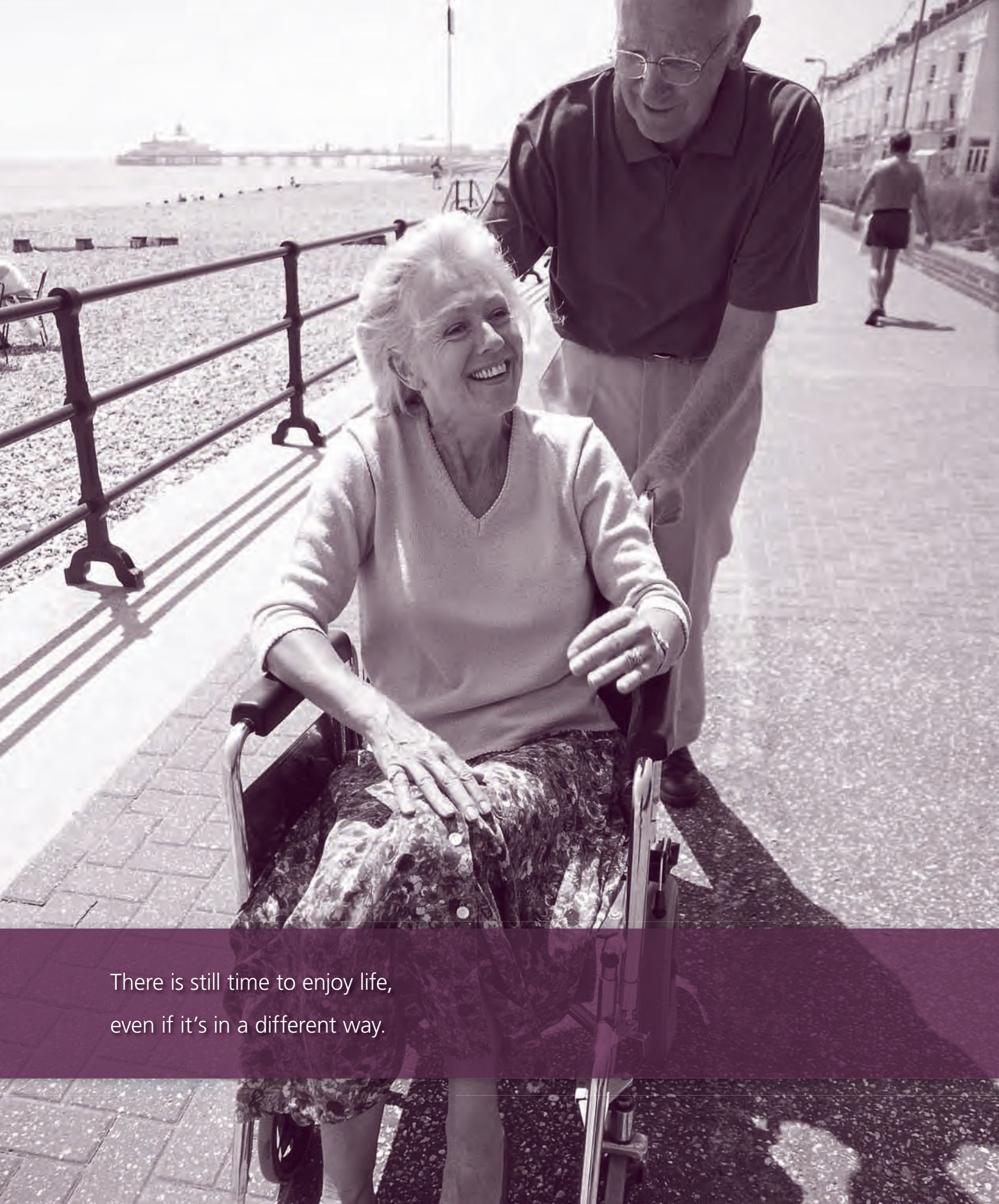
Many caregivers may be unable to care for loved ones at home who are in the final stage of Alzheimer's disease. While the decision to move the person to a nursing home is extremely difficult, it may be the best option. The wisest choices are made when the transition is planned well in advance. Waiting too long could precipitate a traumatic event and necessitate quick action. Family members should consider the needs and wants of both the person with Alzheimer's as well as the caregiver when choosing a facility.

The following may be helpful in deciding on a facility:

- Gather information on options soon after diagnosis, so that if the need arises, it will be available.
- Find local facilities and set up an appointment to evaluate the accommodations, activities, programs and services offered; also make unannounced visits.
- Look closely at staff and their interaction with residents; find out if employees are trained to deal specifically with Alzheimer's disease.
- Observe the demeanor of residents and talk to family members.
- Ensure that the nursing home is clean, well lit, free of unpleasant odors and has an acceptable noise level.
- If the individual is prone to wandering, check on security.
- Ensure that the nursing home is licensed and certified. Review posted surveys.
- Carefully review payment options and agreements or contracts.

More information on finding and selecting the appropriate nursing home is available on internet sites in the Resource List.





There is still time to enjoy life,  
even if it's in a different way.



# SOME FINAL WORDS

**Many people diagnosed with Alzheimer's report that the more they know about the disease, the better they feel.** Learning, knowing what to expect and sharing thoughts and information with loved ones, others who have the disease, professionals and members of support groups, can help people feel more in control, less anxious and better able to take advantage of the current treatments and available sources of assistance.

The organizations and publications listed in the back of this booklet are valuable resources.

After adjusting to the new diagnosis and preparing for the future, the emphasis should be on living and coping with the disease. There is still time to enjoy life, even if it's in a different way. Those with Alzheimer's and their loved ones can find comfort and support in an ever-growing network of information, new treatments, lifestyle recommendations and resources.

There is not yet a cure for Alzheimer's disease, but a tremendous amount of research is being carried out by dedicated scientists from around the world. In recent years, real progress has been made. Our understanding of this complicated disease has increased enormously, and as the pieces of the puzzle begin to come together, we move closer to solving the mystery and finding a cure.



# RESOURCES

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## General Information, Resources and Referrals

### Alzheimer's Disease Research, a program of the American Health Assistance Foundation

Resource for latest Alzheimer's disease research news, prevention, healthy choices, treatment and caregiving.

[www.ahaf.org](http://www.ahaf.org)  
301-948-3244 or 1-800-437-2423

*The following organizations are not affiliated with AHAF. AHAF is not responsible for the content of these websites and does not endorse or recommend any particular program offered by these organizations.*

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### Alliance for Aging Research

Provides information on age-related medical discoveries and health topics.

[www.agingresearch.org](http://www.agingresearch.org)  
202-293-2856

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### American Association of Retired Persons (AARP)

Membership organization for people over 50; informative website.

[www.aarp.org](http://www.aarp.org)  
1-888-687-2277 (1-888 OUR AARP)

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### American Federation for Aging Research

Offers information on healthy lifestyles, age-related conditions, and diseases and biology of aging.

[www.infoaging.org](http://www.infoaging.org)  
212-703-9977 or 1-888-582-2327

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### National Council on Aging

Provides information on healthy aging, maintaining independence, and government and private benefits programs; includes news updates of interest to seniors.

[www.ncoa.org](http://www.ncoa.org)  
202-479-1200

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### National Institute on Aging, National Institutes of Health

Conducts and supports biomedical, social and behavioral research and public education to promote healthy aging. Website has database with information on over 250 national organizations that help older people.

[www.nia.nih.gov](http://www.nia.nih.gov)  
[www.nihseniorhealth.gov](http://www.nihseniorhealth.gov)  
(general information)  
[www.nia.nih.gov/HealthInformation/ResourceDirectory.htm](http://www.nia.nih.gov/HealthInformation/ResourceDirectory.htm) (database)  
301-496-1752;  
TTY 1-800-222-4225

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### National Long Term Care Ombudsmen Resource Center

Under "Ombudsmen Locator" find contact information by state on ombudsmen, Offices on Aging, nursing home licensure, Medicaid and other state resources.

[www.ltombudsmen.org](http://www.ltombudsmen.org)  
202-332-2275

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### Senior Citizens Bureau

Provides information for seniors on government programs, counseling, housing, etc. Includes a state-by-state directory for many services.

[www.seniorcitizensbureau.com](http://www.seniorcitizensbureau.com)  
1-888-801-2497 (Elder Info Line,  
24-hour hotline)

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## State and Local Resources

### Healthcare Professionals

Healthcare providers (physicians, nurses, etc.) are the first source of information for those facing health issues.

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### State and Area Agencies on Aging

Each state and territory in the U.S. has an Agency on Aging office located in its capital city, as well as local offices. Check the phone book or online by state and area. They provide information on nutrition and support services, elder rights programs, long-term care, ombudsman programs, legal services, outreach and elder abuse prevention.

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### State Departments of Health and Social Services

Each state in the U.S. has these departments, as well as local offices. They can provide information on support and respite services, facilities, financial assistance, regulations and licensing. Check the phone book or online by state and locality.

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## Caregiving and Caregiver Support

### Caregiver Resource Center (a division of Employee Assistance Professionals, Inc.)

Provides information on caregiving, planning for long-term care services and employee assistance.

[www.caregiverresourcecenter.com](http://www.caregiverresourcecenter.com)  
203-861-9833

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### CarePathways

Created and maintained by RNs to provide access to healthcare information, products and services.

[www.carepathways.com](http://www.carepathways.com)  
1-877-521-9987

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### Children of Aging Parents

Provides information and materials for adult children caring for their older parents.

[www.caps4caregivers.org](http://www.caps4caregivers.org)  
1-800-227-7294

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### Eldercare Online

An online caregiver support group with information and a directory of support groups.

[www.ec-online.net](http://www.ec-online.net)

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### Family Caregiver Alliance, National Center on Caregiving

Information, education, services, research and advocacy for those caring for people with chronic, disabling health conditions.

[www.caregiver.org](http://www.caregiver.org)  
1-800-445-8106

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### Meals on Wheels

Provides information on local meal delivery and congregate meals for seniors.

[www.mealcall.org](http://www.mealcall.org)

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### National Adult Day Services Association

Use the website database to find adult day services.

[www.nadsa.org](http://www.nadsa.org)  
1-800-558-5301

# RESOURCES

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## **National Association of Professional Geriatric Care Managers**

Health and human services specialists who help families care for older relatives while encouraging as much independence as possible. Use the online database to find a geriatric care manager.

[www.caremanager.org](http://www.caremanager.org)  
520-881-8008

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## **National Caregivers Library**

An extensive online library for caregivers with articles, forms, checklists and links to topic-specific external resources.

[www.caregiverslibrary.org](http://www.caregiverslibrary.org)

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## **National Center for Assisted Living (NCAL)**

Represents long-term care providers; contains information for consumers on assisted living.

[www.ncal.org](http://www.ncal.org)  
202-842-4444

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## **Safety and Home Healthcare**

### **Alzheimer's Disease Education and Referral Center (ADEAR), National Institute of Aging, National Institutes of Health**

One section of the ADEAR website offers information on Alzheimer's-related safety issues, and includes a room-by-room safety checklist (also available as a print publication).

[www.nia.nih.gov/Alzheimers/Publications/homesafety.htm#room](http://www.nia.nih.gov/Alzheimers/Publications/homesafety.htm#room)  
1-800-438-4380

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## **AllegroMedical.com**

Offers a variety of home healthcare products, including safety products.

[www.allegromedical.com](http://www.allegromedical.com)  
1-800-861-3211

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## **The Alzheimer's Store**

Offers safety products to deal with wandering and other Alzheimer's safety issues.

[www.alzstore.com](http://www.alzstore.com)  
1-800-752-3238

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## **MedicAlert Foundation International**

Offers emblems and chains engraved with the person's membership number, primary medical conditions and the toll-free 24-hour Emergency Response Center number. MedicAlert allows the person to be identified, and can relay key medical facts and notify family contacts.

[www.medicalert.org](http://www.medicalert.org)  
1-888-633-4298  
209-668-3333 (from outside the U.S.)

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## **Fisher Products**

Offers home healthcare products.

[www.fishershops.com](http://www.fishershops.com)  
1-866-804-4042

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## **Sears Home Health Care Specialogue**

Offers a wide variety of home healthcare products for seniors.

[www.searshealthandwellness.com](http://www.searshealthandwellness.com)  
1-800-326-1750



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## **Federal Government Programs and Services**

### **Administration on Aging, U.S. Department of Health and Human Services**

A starting point for information on aging for elders and families.

[www.aoa.gov](http://www.aoa.gov)  
202-619-0724

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### **Alzheimer's Disease Education and Referral Center (ADEAR), National Institutes of Health**

Provides current Alzheimer's disease information and resources.

[www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)  
1-800-438-4380

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### **Centers for Medicare and Medicaid Services, U.S. Department of Health and Human Services**

Offer latest information and resources on Medicare and Medicaid.

[www.cms.hhs.gov](http://www.cms.hhs.gov)  
1-800-633-4227

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### **DisabilityInfo.gov**

Provides people with disabilities information and available government programs on benefits, civil rights, community life, education, employment, housing, health, technology and transportation.

[www.disabilityinfo.gov](http://www.disabilityinfo.gov)  
1-800-FED-INFO (1-800-333-4636)

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### **Eldercare Locator**

Provides resource information for older adults in any U.S. community; referrals to state and local area Agencies on Aging and community-based organizations that serve many elder care needs; English and Spanish speaking information specialists.

[www.eldercare.gov](http://www.eldercare.gov)  
1-800-677-1116

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### **GovBenefits.gov**

A partnership of federal agencies that provides access to government assistance programs.

[www.govbenefits.gov](http://www.govbenefits.gov)  
1-800-FED-INFO (1-800-333-4636)

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### **Medline Plus**

Service of the U.S. National Library of Medicine and the National Institutes of Health that provides information on many health topics.

[www.medlineplus.gov](http://www.medlineplus.gov)

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### **Medicaid**

Program funded by federal and state government to assist those who do not have the resources to pay for healthcare. Check the phonebook or online by state.

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### **Medicare**

Federal program that pays for certain healthcare expenses. Call 24:7 for assistance; English and Spanish-speaking customer service.

[www.medicare.gov](http://www.medicare.gov)  
1-800-633-4227; (1-800-MEDICARE)

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# RESOURCES

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## **National Clearinghouse for Long-Term Care Info, U.S. Department of Health and Human Services**

Offers information on long-term care, planning and payment strategies.

[www.longtermcare.gov](http://www.longtermcare.gov)

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## **National Institute of Neurological Disorders and Stroke, National Institutes of Health**

Provides general information on Alzheimer's disease, websites and some publications on its Alzheimer's disease page.

[www.ninds.nih.gov](http://www.ninds.nih.gov)

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## **Social Security Administration**

Social Security is a program that provides retirement and disability benefits.

[www.ssa.gov](http://www.ssa.gov)  
1-800-772-1213

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## **Financial Assistance**

### **Benefits Checkup, National Council on Aging**

Provides information on federal and state programs that offer assistance in paying for prescription drugs, utility bills, healthcare and other needs of older Americans.

[www.benefitscheckup.org](http://www.benefitscheckup.org)

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## **Hill Burton Program**

The program ended in 1997, but about 300 hospitals and health care facilities are still obligated to provide free or reduced cost care; there is a website directory.

[www.hrsa.gov/hillburton](http://www.hrsa.gov/hillburton)  
1-800-638-0742 (1-800-492-0359 in Maryland)

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## **Partnership for Prescription Assistance**

Helps qualifying patients who lack prescription coverage get the medicines they need through appropriate public or private programs.

[www.pparx.org](http://www.pparx.org)  
1-888-477-2669 (1-888-4PPA-NOW)

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## **RxAssist**

Offers information on patient assistance programs sponsored by pharmaceutical companies that provide free medications to those who cannot afford them.

[www.rxassist.org](http://www.rxassist.org)  
401-729-3284

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## **United Project Community for Better Health**

An online community for those who want access to better healthcare options.

[www.unitedproject.org](http://www.unitedproject.org)

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## Legal Assistance

### American Bar Association

Provides information to help find legal assistance and locate lawyers by state. Part of the website deals specifically with legal issues of aging.

[www.abanet.org](http://www.abanet.org)  
[www.abanet.org/aging/home.html](http://www.abanet.org/aging/home.html)  
1-800-285-2221

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### ElderLawAnswers.com

Find an attorney, resources and information on financial and legal issues of aging.

[www.elderlawanswers.com](http://www.elderlawanswers.com)  
1-866-267-0947

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### National Academy of Elder Law Attorneys

Use the database to find an elder law attorney in the private or public sector who deals with legal issues affecting the elderly and disabled.

[www.naela.com](http://www.naela.com)  
520-881-4005

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## Long-Term Care and Living Options

### American Association for Homes and Services for the Aging

Provides information about and contains a directory of services and care facilities for elders.

[www.aahsa.org](http://www.aahsa.org)

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### Commission on Accreditation of Rehabilitation Facilities

Offers advice on finding an accredited rehabilitation facility.

[www.carf.org](http://www.carf.org)  
1-888-281-6531

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### Helpguide.org

“Senior Housing and Care” section of website provides information on long-term care and housing options.

[www.helpguide.org](http://www.helpguide.org)

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### My Guide for Seniors™

Includes a senior housing guide, including options for those with Alzheimer’s disease.

[www.myguideforseniors.com](http://www.myguideforseniors.com)  
1-800-851-4511

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### MyZiva.net® The Complete Nursing Home Guide

Provides information on finding, selecting and paying for nursing homes.

[www.myziva.net](http://www.myziva.net)

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### seniorDECISION.com

Offers a list of home healthcare and senior housing options by state and area with consumer ratings and reviews.

[www.seniordecision.com](http://www.seniordecision.com)

# RESOURCES

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## **SNAPforSeniors™**

Online database can be used to find local senior housing and availability.

[www.snapforseniors.com](http://www.snapforseniors.com)  
1-888-651-7627

## **Research and Clinical Trials**

### **Alzheimer's Disease Clinical Trials Database**

Database of clinical trials on Alzheimer's disease and dementia underway at sites throughout the U.S.

[www.alzheimers.org/clinicaltrials/search.asp](http://www.alzheimers.org/clinicaltrials/search.asp)

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### **National Institute on Aging, National Institutes of Health**

Provides information on government-sponsored human trials and recruitment, with locations, purpose, eligibility, requirements and phone contacts.

[www.nia.nih.gov/HealthInformation/  
ClinicalTrials.htm](http://www.nia.nih.gov/HealthInformation/ClinicalTrials.htm)  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

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### **CenterWatch Clinical Trials Listing Service**

Provides information about clinical research, including listings of active industry and government-sponsored clinical trials, research on new drug therapies and drugs recently approved by the U.S. Food and Drug Administration.

[www.centerwatch.com](http://www.centerwatch.com)

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### **Alzheimer Research Forum**

Lists trials of potential treatments for Alzheimer's disease and has a section seeking trial participants.

[www.alzforum.org](http://www.alzforum.org)

## **Hospice Care**

### **Caring Connections**

Provides information on advanced care planning, financial matters, caregiving and hospice care.

[www.caringinfo.org](http://www.caringinfo.org)  
1-800-658-8898;  
Spanish Helpline: 1-877-658-8896

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### **National Association for Home Care & Hospice**

Click on "Consumer Information" to access database of local hospice providers.

[www.nahc.org](http://www.nahc.org)  
202-547-7424

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### **National Hospice and Palliative Care Organization**

Use website to locate member hospices.

[www.nhpco.org](http://www.nhpco.org)



# HELPFUL READING

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## **Alzheimer's Disease Research (ADR), a program of the American Health Assistance Foundation (AHAF)**

The following publications are available in English and Spanish:

- *Care for the Caregiver: Managing Stress*
- *Safety and the Older Driver*
- *Staying Safe: Wandering & the Alzheimer's Patient*
- *Through Tara's Eyes: Helping Children Cope with Alzheimer's Disease* (English only)
- *Understanding Alzheimer's Disease: It's Not Just Forgetfulness*

**To order ADR publications call 1-800-437-2423  
or go online at [www.ahaf.org](http://www.ahaf.org).**

## **General Information**

*Aging With Grace: What the Nun Study Teaches Us About Leading Longer, Healthier, and More Meaningful Lives* by David Snowdon, 2002.

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*Alzheimer's From the Inside Out* by Richard Taylor, 2006.

A collection of 80 short essays gives readers a rare exploration of the world of individuals with Alzheimer's disease.

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*Into the Mist: When Someone You Love Has Alzheimer's Disease* by Deborah Uetz, Xlibris Corp., 2005.

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*Please Take Me Home Before Dark: One Family's Journey with Alzheimer's Disease* by Billie J. Pate and Mary Pate Yarnell, Providence House Publishers, 2006.

Provides information, inspiration and support to family members and caring professionals of Alzheimer's patients (and those with other forms of dementia).

## **Biographies**

*Dancing with Rose: Finding Life in the Land of Alzheimer's* by Lauren Kessler, Penguin Group (USA) Inc., 2007.

One journalist's riveting and surprisingly hopeful look at Alzheimer's, the disease that claimed her mother's life.

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*The Long Goodbye* by Patti Davis, Random House, 2004.

Ronald Reagan's daughter writes with moving openness about losing her father to Alzheimer's disease.

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*The Long Good Night: My Father's Journey into Alzheimer's* by Daphne Simpkins, Grand Rapids, MI; Wm. B. Eerdmans Publishing Co., 2004.

A powerful portrait of a close family whose bonds are strained but ultimately strengthened by the challenge of caring for the author's father.

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*Losing My Mind: An Intimate Look at Life with Alzheimer's* by Thomas de Baggio, New York, NY; The Free Press/Simon & Schuster, 2002.

A first-person account of the author's early experience with Alzheimer's disease and its effect on his life and his family.

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*Mothering Mother: A Daughter's Humorous and Heartbreaking Memoir* by Carol D. O'Dell, Kunati Inc., 2007.

Chronicles the author's decision not to put her mother, who has Alzheimer's and Parkinson's disease, in "one of those homes" and relays the far-reaching consequences this choice had on her entire family.

# HELPFUL READING

## Caregiving

*The 36-Hour Day: A Family Guide to Caring for People with Alzheimer's Disease, Other Dementias, and Memory Loss in Later Life* by Nancy Mace and Peter V. Rabins, 4<sup>th</sup> Edition, Johns Hopkins University Press, 2006.

Updated classic family guide to caring for people with Alzheimer's and other dementias.

*Alzheimer's Activities: Hundreds of Activities for Men and Women with Alzheimer's Disease and Related Disorders* by B.J. Fitzray, Windsor, CA, Rayve Productions, 2001.

Includes creative ideas for special occasions and everyday activities, caregivers' anecdotes, helpful tips and encouragement.

*Alzheimer's Disease: The Dignity Within: A Handbook for Caregivers, Family, and Friends* by Patricia R. Callone, Barbara C. Vasiloff, Roger A. Brumback, Janaan Manternach, and Connie Kudlacek, New York, NY, Demos Medical Publishing, LLC, 2006.

Caregivers will be better equipped to nurture the dignity within people living with Alzheimer's and feel more confident doing so.

*The Alzheimer's Healthcare Handbook: How to Get the Best Medical Care for Your Relative With Alzheimer's Disease, In and Out of the Hospital* by Mary S. Mittelman and Cynthia Epstein, New York, NY, Marlowe and Company, 2003.

Offers clear explanations and advice on meeting the medical needs of loved ones with Alzheimer's and meeting caregivers' needs as well.

*A Caregiver's Guide to Alzheimer's Disease: 300 Tips for Making Life Easier* by Patricia R. Callone, Barbara C. Vasiloff, Roger A. Brumback, Janaan Manternach, and Connie Kudlacek, New York, NY, Demos Medical Publishing, LLC, 2006.

Offers pointers and guidelines for focusing on the capabilities that remain instead of those that have been lost.

*Creating Moments of Joy for the Person with Alzheimer's or Dementia: A Journal for Caregivers* by Jolene Brackey, 4<sup>th</sup> Edition, Purdue University Press, 2007.

Provides advice on handling the challenges of caregiving and effectively coping with dementia.

*A Dignified Life: The Best Friend's Approach to Alzheimer's Care, A Guide for Family Caregivers* by David Troxel, 2002.

Provides a complete model for the "Best Friends" method of care built around creative and effective communication and meaningful activities.

*Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease* by Joanne Koenig Coste, New York, NY: Houghton Mifflin Company, 2004.

Emphasizes validation of patient feelings and finding joy with the patient.

*Management of Challenging Behaviors in Dementia* by Ellen K. Mahoney, Ladislav Volicer, Ann C. Hurley, Boston, MA, Health Professions Press, 1<sup>st</sup> edition, 2000.

Presents a care philosophy describing proven ways to reduce or eliminate challenging behaviors by addressing their underlying causes.

*There's Still a Person in There: The Complete Guide to Treating and Coping with Alzheimer's* by Michael Castleman, Dolores Gallagher-Thompson, and Matthew Naythons, Penguin Group (USA) Inc., 2000.

Presents a new understanding of Alzheimer's that is optimistic, courageous and comforting.

## For Families

*Singing with Momma Lou* by Linda Jacobs Altman, Lee and Low Books Inc., 2002.

Helps with understanding aging and intergenerational relationships.

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*What's Happening with Grandpa?* By Marie Shriver, Little, Brown Books for Young Readers, 2004.

Offers a touching, optimistic story that encourages awareness, acceptance and dialogue with family and friends.

## Death and Dying

*Understanding Dying, Death & Bereavement* by Michael R. Leming and George Dickenson, 6<sup>th</sup> Edition, Thomas Wadsworth, 2006.

Updated edition remains solidly grounded in theory and research, but places greater emphasis on helping the individual cope with death and dying.

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*When the Dying Speak: How to Listen & Learn from Those Facing Death* by Ronald Wooten-Green, Loyola Press, 2002.

Gives a glimpse of the spiritual reality known only by those nearing death.



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